

Rep. Louise M. Slaughter (NY-28) announced that the Title II provisions of the Genetic Information Nondiscrimination Act (GINA), barring employers from discriminating against an employee based on either his/her genetic information, will go into effect November 21, 2009.

“We are all potential victims of genetic discrimination. With the implementation of these protections, an employer will no longer be able to hire or fire someone based on their genetic make-up,” said Slaughter. “By prohibiting the improper use of genetic information, Americans will be encouraged to take advantage of the tremendous life altering potential of genetic research. It took thirteen years to pass GINA, and I just wish that Senator Kennedy, who worked tirelessly with me on this bill, was here to see this day.”

An audio statement from Slaughter can be found at: http://www.louise.house.gov/images/audio_slaughter/2009.11.17.lmsgina.mp3

Background

Slaughter introduced the first genetic antidiscrimination bill in 1995.

Rep. Slaughter, along with Rep. Biggert (R-IL-13), Rep. Eshoo (D-CA-14), and Rep. Walden (R-OR-2), introduced H.R. 493, the Genetic Information Nondiscrimination Act on January 16, 2007. In April 2007, the House passed H.R. 493 by an overwhelming vote of 420-3.

The Senate had twice passed GINA unanimously in previous Congresses. However, during the 110th Congress, there was a hold placed on the bill in the Senate. The yearlong hold was released after lengthy negotiations, and the Senate passed GINA 95-0 on April 24, 2008.

The House affirmed its support for the Senate approved language by a vote of 414-1 on May 1,

2008.

On May 21, 2008, GINA was signed into law by President George W. Bush and became public law 110-233.

Title I of GINA, the health insurance protections, was implemented on May 21, 2009.

H.R. 493: The Genetic Information Nondiscrimination Act (GINA)

The purpose of this legislation is to protect individuals from discrimination in health insurance and employment on the basis of genetic information. Establishing these protections will allay individual's concerns about the potential for discrimination, encourage individuals to participate in genetic research, and take advantage of genetic testing, new technologies, and new therapies.

Title I – Health Insurance

- Health insurers are prohibited from canceling, denying, refusing to renew, or changing the terms or premiums of coverage based solely on a genetic predisposition toward a specific disease. The bill applies to employer-sponsored group health plans, health insurance issuers in the group and individual markets, Medigap insurance, and state and local non-federal governmental plans.

- The HHS Standards for Privacy of Individually Identifiable Health Information (medical privacy regulations) (45 CFR Parts 160 and 164; final rule) already protect the use and disclosure of all individually-identifiable health information, including genetic information. However, a permitted 'use' of health information under the privacy rules is insurance underwriting. The bill expressly bans the use or disclosure of genetic information for purposes of underwriting.

- The bill amends the applicable laws—the Employee Retirement Income Security Act, Public Health Services Act, Social Security Act, and Internal Revenue Code and generally uses the same mechanisms to enforce the protections established under this legislation as apply to other violations of these underlying statutes. For group health plans and health insurance issuers, the appropriate Secretary may impose penalties of \$100 per day/per person, with a minimum penalty of \$2,500--up to \$15,000 for multiple violations that are more than de minimis, with an outside cap of up to \$500,000.

- With regard to the privacy provisions established by this legislation, the same enforcement structure and penalties created by the Social Security Act for the HHS privacy standards apply. The genetic privacy provisions are enforced by the HHS Office of Civil Rights. The Secretary of HHS may impose civil monetary penalties of \$100 per violation--up to \$250,000 and 10 years in prison for violations committed for commercial advantage, personal gain, or malicious harm.

Title II – Employment Provisions

- Title II bars employers from using an individual's genetic information when in hiring, firing, promotion, and other terms and conditions of employment. This prohibition applies to employers, unions, employment agencies, and labor-management training programs.

- Employers, labor organizations, employment agencies, and joint labor-management committees generally are prohibited from requesting, requiring, or purchasing genetic information about an employee or family member, except for a few legitimate reasons. For example, the purchase of commercially and publicly available documents or inadvertently requesting or requiring family medical history would not violate this title. Under each of the exceptions, the genetic information still could not be used or disclosed.

- The legislation protects applicants or employees of private employers as defined under the Civil Rights Act of 1964 (42 U.S.C. 2000e(f), State employees, Federal employees, Congressional employees, and employees as defined in 3 U.S.C. 411(c). Claimants are required to file a charge with the appropriate enforcement agency within a certain time period, prior to filing a suit in court. The bill provides for the same compensatory and punitive damages available to prevailing plaintiffs under 42 U.S.C. 1981a.